

No Kings ride this morning; attended a medical conference instead (????!!!)

| | AOP2014 | Control | RR [95% CI] (AOP2014/Control) | P-value |
|--|------------------|------------------|----------------------------------|---------|
| Complete Hematologic Response at M24 | 70.5% (67/95) | 49.3% (33/67) | 1.42 [1.09-1.87] | 0.0101 |
| CHR & Improvement in Disease Burden at M24 | 49.5% (47/95) | 36.6% (26/71) | 1.34 [0.93-1.92] | 0.1183 |
| Partial Molecular Response at M24 (LOCF) | 68.1% (64/94) | 34.7% (26/75) | 1.85 [1.33-2.56] | 0.0002 |

Ropeginterferon alfa-2b induces high rates of hematological, clinical and molecular responses after 24 months of treatment

One of many, many, many slides with information relevant to my status as someone afflicted with a Myeloproliferative Neoplasm. I'd much rather learn about bicycle doping. :-)

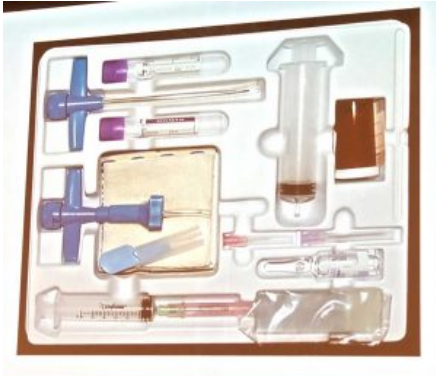
Got to admit it felt really strange, getting up at the regular time for the regular Tuesday/Thursday-morning ride, but instead of getting Kevin up, I took a shower, got dressed, and rode my bike. To the shop. Wrong direction! At the shop I switched from my nice bike to the shop klunker, and headed to catch a train to San Mateo. Felt like a regular commuter, taking a train full of bikes and people to their jobs in the 'City. Got off and rode just over half a mile to a corporate campus (Franklin something-or-other) where there were tons of places to park fancy cars, lots of fancy buildings and... no bike racks! Seriously?



An early discussion panel featuring some of the best & the brightest medical minds in their field.

So why was I here, instead of riding through the steep part of Huddart Park on my way to Kings? Because it was time to associate with my "other" peeps. I got the regular titles, cyclist, dad, husband, biz owner. But there's also that other title I acquired a year ago May. Chronic Myeloproliferative Neoplasm guy. A type of "mild" bone marrow cancer, specifically Essential Thrombocythemia. Part of a family that includes Polycythemia Vera and Myelofibrosis. Stuff that scared the crap out of me at diagnosis but I've gradually come to terms with it over time. And now, it was time to hear from the experts, in a room with others similarly afflicted. My peeps.

These peeps aren't going to be seen riding a bike fast up Kings, although one woman had recently run a half marathon. Mostly they're my age or a bit older. They don't look different from anybody else, although in general they're suffering from various chronic ailments like bone pain, fatigue & headaches. Things that fortunately haven't found their way home to me. But it seemed like a good idea to attend a function where my other peeps got to hear from a panel of 5 or 6 experts in the field and get informed about the latest drugs, clinical trials, and prognostic breakthroughs. Yes, with enough data they can now offer a reasonable idea of how long you've got. But... do you want to know? They actually didn't get into that question, which surprised me.



These are the tools of torture used to perform a bone marrow biopsy.

Turns out I've got until Sept 20th, 2026. **JUST KIDDING!!!** I don't actually fit into the prognostic formulas, partly because I haven't had the latest super-advanced genetic mutation testing, and partly because that testing is likely irrelevant because my primary mutation is, frankly, the best one to have. Life expectancy is generally normal, even if my disease "progresses" to the nasty end-stage that, ironically, my father died from 30 years ago. In my case, it ain't got no teeth. It's possible I could pick up additional mutations along the way, but so could anybody else.

They even had a bone marrow biopsy specialist there, explaining the procedure for getting samples... that's fine... but did they have to show the slides with the equipment they use? Equipment being hand-held needle/punch hybrids? Somehow I got through it.

Overall it was very worthwhile. It felt good to confront my mortality head-on in a deliberate fashion. I learned some interesting new stuff, but mostly it was about finding my place in this alternative community I've acquired. I guess it's not really alternative, but I see it that way because it's not something I had a hand in choosing.

Heading home, I got to the San Mateo (Hillsdale actually) station just as a train was leaving. If I'd known the station better, I probably could have made it. Next train, 15 minutes. Not a big deal but... I'm on a bike... why not ride the 6 or 7 miles back? Maybe I can even beat that train! Didn't quite beat the train, but would have, if not for the zillions of traffic lights on El Camino! Also, I feel a LOT safer on a road bike, with narrower bars, than a mountain bike. On the other hand, on the old beater mountain bike, when a car looked like it might get in my way, I had this feeling of "Yeah, just try it, bring it on!" Was also thinking of one of the Star Trek movies where The Borg have defeated Worf's battle cruiser so, for his presumed final command, he yells out "Prepare for ramming speed!" :-)